

**HIV/AIDS in a rural community in Uganda: Perceived and
objective social factors affecting the HIV epidemic.**

Case reports and a brief review of literature

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2.0 Abstract

Previous surveys have explored factors that may affect HIV prevalence, incidence, and the implications of the epidemic in Rakai and in other African communities. Yet bystanders are often at loss in understanding the personal experiences in a selected community. In five case reports and in an interview with the founder of a local support group, we examine the self-perceived important issues, in the wake of the HIV-epidemic. Through the literature we seek to verify the findings and study the implications for control of the epidemic in a selected community.

Four out of five cases reported that they had experienced HIV related stigmatisation. A majority of the cases also reported withholding information about their HIV status from close family. Furthermore, four out of the five cases cited poverty and lack of food or nutrition as the most difficult part of living with HIV. The surveys reviewed in this report support our findings concerning HIV and stigma, and suggest that HIV related stigmatisation may delay HIV testing, disclosure of HIV status and adversely affect treatment compliance. The reviewed literature also showed that consistent condom use in this population is low and that poverty may have major consequences for the afflicted and their families. Furthermore, those with the highest risk of HIV infection are less likely to accept voluntary testing and counselling (VTC). Moreover, VTC has no effect on HIV incidence and sexual risk behaviour in this area. Our findings highlight the importance of interventions targeting HIV related stigmatisation and poverty in this area.

3.0 Introduction

By 2006 an estimated 38.6 million people worldwide were living with HIV, 4.1 million were newly infected, and 2.8 million lost their lives to HIV/AIDS [1]. Sub-Saharan Africa has just 10% of the world's population, but is home to over 60% of all people living with HIV; an estimate of 25.8 million people are infected with HIV in this region [1]. Uganda is often cited as the success story in sub-Saharan Africa in its efforts to reduce the prevalence level of HIV/AIDS. Among pregnant women in Kampala prevalence level fell from an estimated 30% in 1992 to approximately 12% in 1998 [2]. In 1992 national adult HIV seroprevalence in Uganda was estimated to be 13% [3]. In 2005 national adult HIV prevalence was approximately 6.7% [1].

In 1982 the first reported case of AIDS in Uganda was seen in Kasensero village in Rakai District [4]. The following year, 17 more cases were reported [4]. In 1987 the first cohort study exploring this new disease was carried out in this same district [4]. From then more than 50 surveys exploring HIV/AIDS have been carried out in Rakai District, and more than a hundred articles have been published on the subject.

Several studies have shown that having multiple sexual partners increases the risk of HIV acquisition [5-7]. In sub-Saharan Africa widows and divorcees reportedly have a higher prevalence of HIV infection than other women [5, 8]. Other studies have pointed towards age difference between sexual partners as an important behavioural risk factor for HIV acquisition [6, 9-11]. In sub-Saharan Africa there are reports of many other independent factors adversely affecting the epidemic such as prostitution, travelling, mobility, coercive sex, polygynia and stigmatisation of afflicted individuals [12-15]. However regions may differ and local

traditions such as re-marrying widows or marked age differences between sexual partners may influence the epidemic [5, 6, 8-11].

The most recent estimate of HIV prevalence in Rakai District we were able to find dates back to 1998. HIV prevalence in Rakai District was then estimated to be 16.1% [16] whereas the countrywide prevalence at the time was 7.3% [3]. One study reports that 73.5% of adult deaths were attributable to HIV infection in this area [16]. Infants born to HIV positive mothers have more than twice the mortality rate compared to HIV negative mothers [16]. These figures suggest the district is severely affected by the HIV epidemic. However, figures do not necessarily reflect what local residents perceive as the primary problems due to the HIV epidemic. Neither do the figures say much about implications on everyday life in the particular region. Through case reports in a chosen area we explore the self-perceived implications of the HIV epidemic as presented by the afflicted themselves and in the order they wished. The paper further explores these issues in the amply available literature from the exact same region.

4.0 Methods

The study area and population

Rakai District lies on a plateau in southern Uganda. It has rich soils that support agriculture. The district borders Masaka in the north, Mbarara in the west, Lake Victoria in the east and the Republic of Tanzania in the south. The district covers 4908 sq. km, has tropical temperatures and heavy rainfall almost all the year around. The population was in 2006 estimated to be 471,806 people, mainly made up of people with Baganda tribal heritage [17]. The common languages spoken are Luganda and English. The common faiths in the district are Protestantism, Catholicism, and Islam. The economic activities in the area are mainly agriculture, with commercial and subsistence farming. The most common food crops are maize, beans, finger millet, bananas, cassava, sweet potatoes, coffee, as well as passion fruit, tomatoes and pineapple. A fraction of the population is small holding cattle keepers. Rakai District has 3 major trading centers, and one smaller rural town; Rakai T. C (Town Council); which serves as the administrative headquarters of the district. In 1991 the literacy rate in the district was estimated to be 54%¹ [18].

Availability of HIV health services and research

There are 2 hospitals in Rakai District: Rakai Government Hospital, and Kalisizo Government Hospital, each with 60 beds. In addition to the hospitals, the population in Rakai District has access to numerous health care clinics scattered around in the district. The government is responsible for 41 dispensaries, 21 county health clinics, and 2 sub-county health clinics. Different NGOs (Non-Governmental Organisations) are responsible for 37 dispensaries, 28

¹ In persons aged 10 years and above

clinics, and 1 county health centre [17]. The dispensaries and health centres provide health care services that vary from large wards with admitted patients to smaller buildings with clinical officers and nurses treating out patients.

Literature searches

The Rakai Health Sciences Program was initiated in 1988 as The Rakai Project [19]. The aim of the project was to study the magnitude and dynamics of the HIV epidemic [19]. It represents a collaboration between the Uganda Virus Research Institute of Uganda's Ministry of Health, researchers at Makerere University, Kampala, Johns Hopkins University, Baltimore, and Columbia University, New York [19]. Under this program, the numerous trials and surveys that have been carried out to describe the HIV epidemic constitute an extensive amount of information on the HIV situation in the chosen area. A review of literature was performed on the subjects as follows:

- (a) The use of condoms
- (b) Efficacy of testing and voluntary counselling as an intervention strategy
- (c) Exploring self-reported consequences of the HIV epidemic on individuals
- (d) Behavioural factors affecting the HIV epidemic in the selected area
- (e) Prevalence and incidence of orphanhood associated with HIV/AIDS

The literature and articles used in this report were gathered from the internet using the PubMed and Medline digital archives using the following search words: HIV, Rakai, Uganda, prevalence, incidence, orphanhood, widowhood, re-marriage, travelling, polygynia, stigmatisation, sub-Sahara, Africa, prostitution, condoms, risk factors, risk behaviour, quality of life.

Interviews

Interviews with HIV positive individuals in Rakai District were performed in December 2005 and January 2006. The individuals were not randomly selected, but were chosen on the mere basis of social acquaintance. An interview with the head of a local HIV support group was carried out. Where necessary interviews were performed with the aid of a local person acting as an English-Luganda interpreter.

Ethical Considerations

District health authorities in Rakai gave written consent to the study. All the subjects were informed of the aims of the interviews, and all participants gave informed and free oral consent. All the participants are anonymous in this report and the report will not be published before each person has read and accepted the final version of the report. Every effort was taken to show respect for cultural and religious values, and every effort was taken to ensure confidentiality. Furthermore, no incentives were given.

5.0 Case Reports

Case Report 1.

A 34-year old man tested positive for HIV in 1994. He is a protestant, working as a writer, and a widower. He could tell us that he suspected he was infected several years prior to taking a free HIV test at a clinic. His fiancée had died when he was 18. Shortly before her death she had told him that she had tested positive for HIV. They had been going out for 3 years. He describes the moment he received the positive test result as "devastating" and told no one about the test. He first told someone about his HIV status 5 years ago. Standing out was "a shame", and his father, a reverend, stopped paying his college fees. "My friends avoided me and kept saying I shouldn't say it. You see, people don't want to talk about it." His wife, his fiancée, and 4 of his sisters have all died of HIV. His brother and his sister-in-law have both tested positive.

When asked why he believes people avoid HIV testing, even if they suspect they are HIV positive, his answer is simple; "stigmatisation". He says: "If I speak to a woman in the village, 10 minutes later someone will come up to her and say: Don't speak to that man, he has HIV". He continues: "People think I am a womaniser just because I have it." He says that prostitution is quite common in Uganda. As a consequence, those who chose to be open about their positive HIV status will be associated with prostitution. To avoid losing ones lover, husband, or wife, people simply avoid HIV testing. He says that these are also the reasons why people might avoid informing their partners and family that they've had a positive HIV test: "I think there are a lot of people who do not tell. They are afraid of being chased away by their partners, so they keep it a secret."

The man further points to other reasons for people not testing for HIV and not coming forth. "Some people believe that they will lose their business if they confess. When you talk of AIDS in Uganda it is like a curse. People tend to think that they are cursed, that they are outcasts if they confess their status. So they prefer to keep their secrets to themselves. There are also a lot of people who refuse to test and a lot of families breaking up because of this."

He has now been a member of a support group for 2 years. Joining the forum has helped a lot; he is now counselling friends about HIV, the same friends who avoided him after he declared he was HIV positive. He feels that the hardest part of living with HIV is being marginalised, but he says this has become better and most people are now sympathetic. He has, in his own words, a lot of signs of the disease. He has used Septrin^{TM2} for several years, but is not on the ARV (Anti-retroviral therapy) programme. He further says that he has abstained from sex for 1 year. He believes most HIV positives use condoms, but feels that abstaining from sex suits him better.

When asked what he believes are the major challenges in fighting the HIV epidemic in Uganda in general, and in Rakai specifically, he answers: "We have to fight the stigma. If we can make people stand out and confess about their status, more people will take the tests, more people will show up for the ARV treatment. Right now lots of people who are sick don't show up at the hospital for medication, because they fear someone will see them. Also, if people are open about their status, spreading of the virus will decrease." Another major challenge is all the orphans the HIV epidemic has caused. "70% of families in Uganda must now have orphans." He finishes: "Everybody's affected by HIV here now. If you haven't lost

² Pharmaceutical used in Uganda, contains Trimetoprim (80mg) and Sulfonamide (400mg)

a brother or a mother, you've lost a friend or a cousin. The good thing is everybody knows about HIV now".

Case Report 2.

This woman of 32 years of age tested positive for HIV when she was 26. She was born in a small village in the district, and has lived there her entire life. She is a Muslim, works as a subsistence farmer, and has 5 children, all in school. Her husband died when she was 25 and she has been a widow since. When asked how she thinks she has acquired the virus, she answers: "I got it from my husband, it is the only way possible. " He never undertook an HIV test, and she had no idea he was HIV positive. She decided to take an HIV test when she kept falling sick. She suspected it was because of HIV. Her reactions to the positive test result were fear. She told her relatives right away, but not her children, they realised "as time went by". Her relatives became worried when she informed them about the HIV test, but she comforted them, something she says she still does. She also has experienced discrimination and stigmatisation because of her positive HIV status. Some people have stopped contacting her as a result of her status. When asked about her current medical situation she answers: "My face itches, I scratch it, and then my skin peels off". She feels weak and has problems handling her work as a farmer. She tells us she has been on the ARV programme for almost 1 year. She feels the tablets give her help, but continues: "But they tell me to eat fruits and concentrate on nutrition, but I don't have the money." Prior to entering the ARV programme she started using Septrin™ when the hospital had it in stock, and it was free of charge. When asked what she feels are the most difficult parts of living with HIV, she answers: "Before I got the disease I was able to work for my kids, but now I am weak, and I can't dig, I can't have a job. So I can't buy food or pay for my children when they are sick. Also, it is hard having HIV and being a Muslim. For example, I can't do the fasting. It is too hard." She tells

us that her children help her in many ways; they do the digging when she is weak, and when she is in hospital, they go there to care for her (bring food, do her laundry, and wash her³). We ask the woman what she wants a doctor to know about HIV, and she answers us "I want them to know that because I am sick, I can't sustain myself anymore. We need other help, not just tablets. We need money for sugar, soap, for clothes, for other treatment."

Case Report 3.

A woman, 43 years old, believes she was infected 13 years ago when she got married. She believes her husband, who died last year, was the one who passed her the HIV virus. "How else could I have got it? He had all the signs of it when he died. He also had a mistress who died of HIV." He never took an HIV test, though the doctors as she puts it, "begged him to". She is a catholic, and has 3 children. Today she is working as a volunteer worker for a support group. She decided to take an HIV test because her husband was very weak at that time, constantly losing weight. She suspected she was HIV positive. Seven years ago she told her family, but not her husband or children. Two years later she told her children. When asked how her family reacted to the fact that she was HIV positive, she says they gave her a positive answer. They took her straight to a hospital to get treatment, and have helped her with the children up through these years. "I remember my mum said that "my daughter is going to die", but my father comforted her. My father is so proud of me!" She says she did not tell her husband about the test or the result. He had told her earlier that he would not want to know about the test if she decided to take one. "He was afraid of the stigma." She believes there are 2 major reasons that cause people to worry about stigmatisation. First, they fear for rumours and talk. Second, they fear for "not being able to marry".

³ Author's note

She has been taking ARVs for 3 years now; the first 1.5 years she had to pay for the treatment. She has used Septrin™ for 2 years. At the time of the interview she has run out of Septrin™. The first years she was aware of her HIV status she received no medical treatment, but took local herbs because it was cheaper. She feels the ARVs have improved her condition substantially, but is worried global politics may interfere with the programme. “If President Museveni continues to behave as he does, perhaps we lose it, because of less donor aid.” Her children have all undergone HIV tests, and they are all HIV negative. One of her sisters died of AIDS last year, 29 years old. She left one child. Her sister’s husband died of AIDS many years back. “I was also pregnant after I tested positive, and I was very frustrated and scared; was I to give birth to an HIV positive baby? It ended with an incomplete abortion.”

When asked what the most difficult parts of living with HIV are she answers: “Poverty. Constantly you ask yourself, do you have things to eat and drink? The times you spend bedridden are the worst. People give what they have of food. You want transport to the hospital for treatment, but you can’t afford it.” She believes the biggest challenges in fighting the HIV epidemic in Uganda is for the aid to reach the villages. As she puts it: “The support is there, but people in the villages don’t get it.” Another challenge is to succeed with incorporating people with HIV in to the work with HIV and AIDS. She sums up: “People with HIV don’t get jobs as HIV counsellors. We’re not represented.”

Case Report 4.

A 59 year-old man from Rwanda of Catholic faith moved to the district 9 years ago because of the genocide in his former country. He is a peasant and was married in Rwanda. There he had a family of 10, but currently he lives alone. He first tested positive 3 years ago. In contrast to the other individuals interviewed he says he was happy when he received the

positive test result. It meant that he now could receive medicine and care for what he was suffering. He told a community member about the test. “They (the community⁴) feared, and kind of socially isolated me. But when I got the ARV treatment and got better, they came back.” He believes he was infected with HIV 5 years ago. He fell in love with a woman outside of marriage and they slept together. “I didn’t know her very well. It was my only affair.” Four years ago he suspected strongly he was HIV positive. He confirms that there are a lot of people that avoid HIV testing, and believes this is because “they have fear in themselves. They don’t want people to know, so they hide.” He believes these are the reasons why some also might avoid showing up for HIV medication at hospitals and clinics.

Three years ago he entered the ARV programme, and feels the ARVs have helped a great deal. “Before I began taking the ARVs I couldn’t eat, and I was scratching myself all the time. Now I can eat, and my skin isn’t itching. I feel I have changed.” Prior to entering the ARV programme he used no medicines at all. “I was very sick before I started on ARVs. I was vomiting and felt tired all the time, had diarrhoea, and was itching. I was very thin; I weighed only 40kg, now I weigh 63 kg.” When asked what he believes are the most difficult parts of living with HIV he answers “First: I worry. When I have a scar, it itches, and I overthink. I think the virus will kill me. Second: HIV has made me unenergetic, so I can’t work. So I have problems getting food. Also, I don’t have the money for transport. I don’t have a problem with people isolating me. Whether it is good or bad, I take it the way it comes.” He is now a member a support group and is actively working with information campaigns and counselling. “Sometimes, when working with counselling, we inform about ARVs, then someone can shout, “Look, that one is infected!” That’s a challenge”

⁴ Author’s note

He feels the government has helped him in many ways; first he was given counselling about life with HIV, secondly he was given free anti-retroviral therapy. He is grateful he knows about his HIV status. He points out that people with HIV can contribute to fighting the HIV epidemic in Uganda, and explains. "We can teach people not to have sex outside of marriage. We could teach them to abstain from sex." He believes the government should focus more on mass education in order to reduce the extension of HIV in Uganda. "Everybody should know about HIV. They should be reaching out to villages, homes, and the public. Also they should give people transport to the hospitals to learn about HIV."

Case Report 5.

A woman of 45 years says she has known she's HIV positive for 21 years. "I knew the virus was in the area and two of my husband's lovers were dead. I felt sick on and off with vomiting. In 1986 I also had a large skin-rash, which was burning. "She was born in the district and has lived there all her life. She is now a protestant, but used to be a Muslim. She is a farmer and has been married since 1980, and has 2 children. Fifteen years ago she took an HIV test, and was terrified when it came out positive. "I had gone to give birth at the hospital. When I was there I thought I should do the test. When I saw it was positive, I thought: Who will look after my children? At that time my children were the ages of 1 week, and 3 years respectively." When her husband came to the hospital to visit her, he found her at the hospitals testing office, not in the maternity ward. "I lied to him; I said I wasn't there for the test. He left the hospital, and left me. A man at the hospital looked after me⁵. After 2 weeks some of the other family members called my husband and said: "Why did you leave? Go back to her." And so he did. I was admitted in the hospital for 3 months. "She told only her brother

⁵ Catered for food, paid medication. Authors note

about the positive test. He also was terrified; both of her sisters had died of HIV and she was the only girl left in the family. So he told her “Now you must die too.”

She waited 9 years before she told her husband about her HIV status. “It was after his mistress died, so he had to know. He feared, but he told me: “Maybe you are sick, but I’m fine. I’m not going to help you; you don’t have to help me. We’ll live under the same roof, but not the same bed.” For all the years after this I have been digging and providing for me and my children. If he wants sex he goes somewhere else. At one time he was also marrying other women⁶, but he came back. We never told anyone about our domestic problems.” At home, she also serves him food and washes his clothes. She confirms that these years have been tough ones, and explains: “Even if it’s Christmas I have to make sure there’s enough food, water, paraffin, clothes. My son is now 15 years. He has heart failure, and is always weak. So he can’t work, and it’s a big challenge.”

Her husband had never tested for HIV, not until the day of the interview. “He never wanted to be associated with HIV. But recently he has been sick. He has been coughing for 4 months, malaria⁷ has been on and off, his legs are swollen, and he’s itching. So today he has come to the hospital with me to take the test.” We ask her if she believes their domestic situation will change if his test turns out positive. She answers: “He lets me live on his land and in his house, but he brings no contributions. I will continue to wash his clothes, cook for him, make his bed, but no sex, he has to contribute for that. I hope he will change after today and ahead.” She says she is not angry with her husband in any way, but blames herself for their domestic problems. She forgives him and says that the problem is that she hasn’t given him sex.

⁶ Polygamy is possible in this area

⁷ Author’s note: synonymous with fever

She says the most difficult part of being HIV positive is the poverty that comes along with it. “Sometimes when I am bedridden, and I don’t have money, nobody’s there to support my children and me. That’s the worst part.” For one and a half years she has been on the ARV programme and feels the medication has helped a lot. She recommends others with HIV to do the same as she did; get tested, stand out, and help others by counselling and sharing information about the HIV epidemic.

5.1 Interview with the founder of a local support group in Rakai District

The forum was founded in 2002. It works to spread information about positive living, providing support to the infected and affected and preventing further spread of HIV in the district. It has increasingly managed to get involved in counselling services in the district in co-operation with the local health services, and several of the forum members work as counsellors at the local hospital.

Could you please give a brief overview of the HIV situation in the district?

- Well, currently there are 1203 people in the district that have openly said they are HIV positive⁸. There is a large group of HIV positive people that don’t want to come forward. In addition, there is a large group of people who suspect they are positive, but they have not yet tested.

Why do you believe the HIV epidemic has come to the extent it has here?

- There are several factors. First there is little use of condoms. Second there is even less use of condoms after people have had a couple of beers. Third, everybody has affairs. People are

⁸ Authors note: The total population of Rakai District: 470,000.

very careless about sex in Uganda, even the young boys and girls. And with the ARVs, even more. Another factor is that older men tend to have more money, so they attract younger women. Often these older men are HIV positive. They transmit the virus to the younger women. Then, when these women marry same aged men, they are positive, and can pass the virus on to their men.

You say that having affairs is common. Does this apply to both men and women?

-Yes, both, but a lot more of the men. If I were to guess I would say 5% of the women, and 50% of men have affairs. Many women have partners outside marriage when they find out the husband has.

Do you believe prostitution contributes to increase the number of HIV infected individuals in this district?

- Well, if the man can't provide money, I believe some women go to the saloon and say: "Give me some cash and a good bag of food, and I will do the service." When they come home they say to the man they were busy digging.

In some countries there are traditions of widows re-marrying. What are the traditions when it comes to the widows in this district?

- There are a lot of men staying at the widows, because there's no trouble, and no fighting. Some marry, some don't. The widows are hopelessly promiscuous just like the men.

What if a person knows about their positive HIV status. Will this change their sexual behaviour?

- No, I believe they keep on as usual. Most people don't think about spreading the virus.

Do people receive information about living with HIV?

- After the test, the hospitals and clinics have no information and counselling service. So people go home and have to find out themselves.

Are there any programs for information?

- Yes, there are programs, but they tend to keep the money⁹. So it doesn't really work.

What about HIV positive pregnant women, do they receive any information? Do they know about the risk of passing the virus on?

- They usually know about their status, but most women don't know about the risk of passing it on to the child. They think, but they are not sure, so they continue to give birth. Now there is counselling to pregnant women at the hospital, which is good. Another large problem we haven't discussed is the problem with orphans; approximately 20% of families in Uganda have one or more orphans staying with them.

How would you like people working with HIV positive individuals to act and treat you?

- Welcome us with a smile. Try to understand our difficult situation. Listen to us. Touch us, we are not dangerous. Give us time, and give us hope.

⁹ and not do much. Author's note.

6.0 Discussion

Stigmatisation

One of our cases waited seven years before he told anyone that he was HIV positive. He believed many avoid HIV testing because of fear of stigmatisation. One of the women presented in the case reports never told her husband about her HIV positive status. Another woman we met in the case reports waited 9 years prior to informing her husband she was infected by HIV. The cases also reported that they had experienced HIV related stigmatisation. Wolfe et al. explored the effects of HIV related stigmatisation among patients receiving ARVs in Botswana [20]. A total of 112 patients were interviewed, 40% of the patients said they had delayed going through HIV tests, 51% of these patients said this was primary because of fear of a positive test result. In qualitative interviews this was often due to HIV related stigmatisation. Furthermore, 94% of the patients kept their HIV status a secret from the community they lived in. 69% of the patients had not told their families about their HIV status, and 30% had not told anyone. These figures support the findings in our report concerning disclosure of HIV status and delay of HIV testing.

A community-randomised trial in Rakai in 1994-1995 [21] examining the use of voluntary counselling and HIV testing in the population showed that women reporting high risk behaviour were associated with low VTC (voluntary testing and counselling) participation. The same applied for women reporting symptoms suggestive of AIDS. The authors suggest that women may experience more adverse consequences of using VTC than men. For instance, the potential negative consequence of abandonment by one's spouse, may have a larger negative effect on women, because "of their relative social and economic

vulnerability.” This study was done before ARVs became freely available, and it is possible that ARVs may have changed the attitude towards testing. If that is correct, it would however be in contrast to what the individuals in our case reports have described.

Porter et al. explored HIV status and union dissolution in Rakai District [22]. The data for the study were drawn from a community based randomised clinical trial conducted in Rakai District. The participants were interviewed every 10 months, 5 times. An individual analysis and a couple analysis was done; the individual analysis consisted of 6433 women, and the couple sample consisted of 4785 women for whom information on their partners were available. The objective of the study was to examine the influence of HIV status on the risk of separation or divorce or widowhood among women in Rakai. Women’s positive HIV status was significantly, positively associated with a greater likelihood of separation or divorce, and with increased odds of dissolution by 94% compared with non-infected women. The results highlighted women’s vulnerability to HIV infection. The authors suggest that stigmatisation of HIV positive women is the probable explanation for the results. However 51% of women initially enrolled in the trial were lost to follow-up before the trial ended, the effects of the drop out on the results of the study are unclear.

In a qualitative study using focus group discussions Pool et al explored the attitudes of women attending maternity clinics to VTC during pregnancy in rural areas in south-west Uganda [23]. A total of 208 women attended 24 group discussions. The survey revealed that several of the trial’s participants were afraid of stigmatisation. Most of the women attending the discussions were positive to HIV testing and counselling, but were concerned about confidentiality. There was widespread fear that maternity staff might not want to help them with the birth if their HIV status was known. Women in the study were also concerned that if

their husbands found out about their HIV status separation, divorce, or domestic violence was likely to occur. Furthermore another study reports that 15% of the patients felt that HIV related stigma made it difficult for them to take ARVs regularly [20].

In summary, the case reports and available literature suggest that HIV positive individuals in this district may fear or experience stigmatisation or punishment in various forms. Disclosure of HIV status may lead to union dissolution, conflict, discrimination and abandonment. As a consequence there is delay in HIV testing, avoidance of counselling or poor ARV compliances as described in several of the case reports. If this is correct, it leaves important possibilities for intervention. One could hypothesise that information programs promoting openness about HIV status, acceptance of HIV positive individuals, family/partner counselling, and high availability of assistance along with absolute confidentiality during VTC may make it easier to receive VTC, get treatment and change sexual behaviour. However, to our knowledge there are no reports from Rakai that have studied the effect of such interventions on HIV prevalence/incidence, and more research may be necessary.

Poverty

Four of the interviewees in this paper say that poverty and lack of food/nutrition is the hardest part of living with HIV. Being unable to work is mentioned as the reason for the poverty by a majority of the individuals interviewed. A qualitative survey from Rakai and Masaka District [24] aimed to examine what local community members considered to be the main problems the HIV epidemic had caused in their community. Fifty subjects from 30 different villages were interviewed. Each resident provided a list of what they felt were the major problems affecting their community due to HIV. Twenty-four of the residents listed poverty/reduced income, poor accommodation, and many orphans as major problems affecting their

community. Other subjects listed deaths of businessmen resulting in lack of jobs, poor nutrition due to no-one left to cook, retarded community development, and stigmatisation and social isolation/hiding as major problems caused by the epidemic. The study commented that “the economic consequences of the epidemic are well known, but the importance of the economic impact given in the interviews is surprising” [24]. In the article the authors added that research on HIV in Africa has so far focused on prevention, but several communities have been devastated by the epidemic and need attention if they are to survive socially and economically.

In two of the case reports women also describe problems of providing enough food, care and support for their children. A study carried out in Rakai District (published 2004, time of conduction not found) examined quality of life among HIV positive mothers with young children using a cross-sectional survey within a large pre-existing cohort. Compared to HIV negative mothers, HIV positive mothers reported significantly lower scores for physical functioning, pain, energy, role functioning, social functioning, mental health, and overall quality of life. HIV infected mothers with more than 4 symptoms reported substantial limitations. For example, one fifth reported feeling depressed. As mentioned by our cases, over 30% of the HIV positive may be limited in conducting moderate activities of work. In the article, the writers pointed to consequences of the findings: “These problems in functioning among HIV infected mothers could help explain reports of higher mortality among children born to HIV infected mothers” [25, 26].

Much of the research on the HIV epidemic in Rakai has been conducted on the causes and outcomes of HIV. Far less has been written on how the affected societies themselves perceive the epidemic. One study reports that “Given women’s central role as household caretakers in

Uganda, interventions aimed at improving the quality of life may improve their physical and mental conditions and that of the family” [26]. This seems to correlate with the impression left by our case reports, where women interviewed reported how their children had to step in as caretakers and food providers when their medical conditions worsened. With background in our case reports and the reviewed literature we believe there may be a need for interventions targeting poverty amongst those affected with HIV/AIDS in Rakai. We hypothesise that support for individuals and families suffering from poverty caused by HIV could have considerable positive effects on the state of nutrition and health of HIV positive and their families. We hypothesise that the long-term effect of HIV on poverty would decrease if children were relieved of the caregiver burdens and could concentrate on school [27, 28].

Risk behaviour

All of the individuals presented in the case reports believe they were infected through sex (heterosexual). In 2 of the case reports mistresses were claimed to play a part in their acquisition of the HIV virus. The founder of the support organisation claimed that sexual promiscuity in the population as one of the important reasons for the HIV epidemic to have reached its current level. She also says condom use is low in Rakai; and lower after ingestion of alcohol. There are numerous surveys and trials that have been performed in Rakai exploring biological and non-biological factors affecting HIV prevalence and incidence. A randomised study in Rakai in 1993 examined risk factors for HIV infection [7]. In multivariate analysis age and the number of sexual partners remained significantly associated with HIV infection for both sexes. Confirming the findings from a large study in 1994-1998 [29], a case-control study in 2000 exploring risk factors for incident HIV infection showed that there was a significantly higher risk of infection in men and women who reported 5 or

more lifetime sexual partners compared to those who reported only one lifetime partner [30]. It is uncertain whether the latter study was conducted in the local district or not and this of course limits the use of it in this area.

The main mode of HIV transmission in Uganda is heterosexual intercourse [31]. A randomised trial showed that consistent use of male condoms may reduce HIV incidence by approximately 80% when the way of transmission is heterosexual intercourse [32]. A randomised trial in rural Rakai District in the years 1994-1998 aimed to describe HIV incidence and STD prevalence associated with condom use [29]. Briefly, 56 communities on secondary roads were grouped into 10 clusters; which were allocated randomly to intervention and control arms. In the study population condoms were free of charge and distributed by the community health workers and clinic facilities. Condom usage information was collected from a total of 17264 sexually active individuals aged 15-59 years over a period of 30 months. HIV incidence and STD prevalence was determined for consistent and irregular condom users, compared to non-users. The trial showed that condom use was generally low in the population; only 4.4% reported consistent condom use, and 25% had ever used condoms. Condoms were used more frequently by the younger and better educated participants. HIV incidence among consistent condom users was much lower than that of non-users (0.97 per 100py (person years) vs. 1.69 per 100py), and was less than half the incidence rate of irregular condom users (2.14 per 100py). In addition, the prevalence of syphilis, gonorrhoea, and bacterial vaginosis were significantly lower among the consistent condom users. The study showed that condom use in general is low in the population; consistent condom use is even lower. Further, it showed that consistent condom use significantly reduces HIV incidence, but that irregular condom use provides no protection.

A prospective study in Rakai [33] from 1995 to 1998 explored the use of contraceptives in this district. As suggested by the leader of the HIV support group condoms use is low in this population. While 10% of men reported using condoms in the first interview, 17% reported condom use in the 4th follow-up. This reveals striking possibilities for more effective strategies promoting consistent condom use but does not suggest how to accomplish this goal.

Moreover, an open community cohort in Rakai examined alcohol use before sex and incident HIV, between 1994 and 2002 [34]. Adults aged 15-49 years were interviewed and tested for HIV 1. The main exposure of interest was alcohol use before sex by one or both partners, and the association with HIV incidence, compared with no alcohol use by either partner as the referent group. The trial also assessed the association between alcohol use before sex and the number of sex partners (two or more partners versus one), having extra-marital sex the last year (yes versus no), and inconsistent condom use in the past six months compared with consistent use. Among individuals who did not drink alcohol before having sex, HIV incidence was 0.9 per 100py among men, and 1.0 for women. HIV incidence was higher when one partner consumed alcohol prior to having sex (1.7 per 100py among men and 1.5 per 100py in women), and was further increased when both partners drank alcohol before engaging in sexual relations (1.8 per 100py in men and 1.9 per 100py in women). Individuals consuming alcohol were more likely to report inconsistent condom use, a greater number of sex partners, and more extra-marital sex. HIV incidence increased with the reported number of sex partners, and in both sexes, HIV incidence was highest in individuals reporting inconsistent condom use. Furthermore, non-Muslims had a higher HIV incidence than Muslims although this cannot be ascribed to alcohol use alone.

In brief summary, the trial showed that alcohol use with sex was common in the population, and was associated with an increased risk of HIV acquisition in both sexes. The use of alcohol was associated with increased risk behaviours, and may indicate that alcohol may affect HIV risk by behavioural dis-inhibition. Again, the study confirms the impression left by the support group. Hence interventions targeting alcohol intake could have positive effects regarding HIV incidence in this district.

Effect of Voluntary Counselling and HIV testing

The leader of an HIV/AIDS support group purported that there are many people in the district who suspect they are HIV positive but avoid the HIV test. The interviewed cases report that people fail to take the HIV tests for various reasons. One of the case reports claims he suspected he was HIV positive several years prior to taking an HIV test. In 2 of the cases husbands refuse to take HIV tests despite having symptoms suggestive of AIDS. A 1994-1995 community-randomised trial in the district enrolled 10950 adults aged 15-59 years, ascertained their HIV status, sociodemographic characteristics, risk behaviours, and AIDS associated symptoms [21]. All subjects were offered VTC free of charge. The trial compared users and non-users of VTC to map population groups willing to undergo counselling and HIV testing. Only 33% of participants who gave blood voluntarily requested and received their results. Young age and HIV positive status were associated with lower VTC participation for both women and men. Women reporting to have 2 or more sexual partners also had low VTC participation. The same applied for women reporting symptoms suggestive of AIDS. Adolescents had the lowest VTC rates in both sexes. The highest VTC rates were seen amongst divorced, separated, and widowed participants. These differences remained significant when corrected for gender. The results suggested that some of the most vulnerable to infection were less likely to participate in VTC. The authors suggest that high-risk

individuals in Rakai might avoid VTC, because they suspect they are HIV positive, and fear confirmation of HIV infection. Results from a similar trial were published in 2005 [35]. The objective of the cohort was to assess the acceptance of VCT, and the effect of VCT on sexual risk behaviour, and HIV acquisition - 10649 adults were interviewed, HIV tested, and were offered free VCT. Risk behaviour and HIV incidence in HIV negative acceptors and non-acceptors was assessed. VCT acceptance was lower among persons with no prior VCT, individuals who were HIV positive, and persons reporting condom use the last six months. VCT acceptance was also significantly lower among persons with education, compared with those with no formal education. VCT acceptance was highest among married and previously married. The results from these two studies seem to confirm our interviewees who described avoidance/delay of HIV testing. In addition the reviewed studies showed no effect of VTC on HIV incidence. If this is correct, it has serious consequences for intervention strategies in this district.

An interviewee says “most people don’t think about spreading of the virus”, and that there is a small chance someone will change their sexual behaviour because of a positive HIV test result. A study has shown that there was no significant difference in sexual risk behaviours, and HIV incidence between VCT acceptors and non-acceptors [35]. The survey concludes that there was no impact of VCT on HIV incidence and sexual risk behaviour. Among the individuals who were HIV positive, only 46.8% accepted the use of VCT. The authors suggested that fear and denial may be important barriers, and underline the importance of interventions to deal with this issue.

Data from the Rakai Health Sciences Program annual cohort have also been examined for the effect of repeat VTC on sexual risk behaviour and HIV incidence in 6377 initially HIV

negative subjects [36]. Repeat-acceptors were significantly more likely to report inconsistent condom use than non-acceptors of VCT. There was no significant difference in consistent condom use between first time users of VCT and those who chose not to accept VCT, and consistent condom use did not differ by number of self-reported sexual partners. Furthermore, there was no significant difference in the number of self-reported sex partners between repeat-acceptors of VCT and non-acceptors. The trial found no significant difference in HIV incidence between those who chose to undergo HIV testing and counselling, and those who chose not to receive VCT. In summary, the survey found that repeat-testers are less likely to change their sexual behaviour, consistent condom use was generally low in the population, and voluntary HIV testing and counselling had no effect on reducing HIV incidence in the area.

Orphanhood

The leader of the local support group in Rakai District mentions in the interview that orphanhood caused by HIV is a major problem in Uganda. She believes 20% of families in Uganda take care of one or several orphans. One of our cases believes orphanhood is a major challenge in fighting the HIV epidemic in Uganda, and believes 70% of all families in Uganda have one or several orphans living with them. In 2005 UNICEF (United Nations International Children's Fund) estimated that Uganda is home to approximately 2.3 million orphans (13.9% of total population under 18 years of age), and that approximately 1 million of these are orphaned due to AIDS [37]. Orphanhood, lack of parental counselling, and difficulty in educating orphans have been listed as major problems by residents in the district [24].

A study from Rakai District showed that a positive HIV status is significantly associated with widowhood (OR 7.56 compared to non-infected women) [22]. A population based community cohort study carried out in the district in 1996-97 tried to assess the incidence and prevalence of orphanhood associated with parental HIV infection [38]. Data was collected from 10657 households, and a total of 22712 children aged 0-14 years were enumerated. Adults were interviewed, provided blood for HIV testing, and were followed up 10 months later to determine parental death and incident orphanhood. The study showed that the prevalence of orphanhood was higher among children of HIV infected parents (22.7%) compared with children of HIV negative parents (7.9%). The prevalence of orphanhood among children of HIV infected parents increased significantly with the child's age; among children 10-14 years old 40% had lost a father, a mother, or both parents due to HIV/AIDS. Furthermore, children of HIV infected parents had a higher mortality compared to children of non-infected parents (3.1 per 100 py vs. 4.8 per 100 py). The annual incidence of orphanhood was 8.2% if at least one parent was HIV positive, compared with 0.5% if both parents were HIV negative.

The findings suggested that if parental mortality due to HIV/AIDS could be eliminated, there would be a 37.3% reduction in the incidence in orphanhood in the area. Although the study was thorough and well designed, it had certain limitations. Parental HIV status was unknown for 50.1% of the children included in the incidence calculation. This could be a source of bias in the estimations made in the study. However, the study supports the statements of interviewees in this study. The findings of this study underline the importance of effective interventions to reduce adult HIV mortality in this population. It also shows that there is a need to provide support for the children suffering from loss of parents due to HIV/AIDS.

Widows, age difference between sexual partners, and coercive sex

Three of the cases presented in this report are widowed. An interviewee believes there are a lot of men staying with widows. A randomised study in Rakai exploring risk factors for HIV infection showed that there was a significant association between marital status and risk of HIV infection (higher risk of HIV infection in widowed/divorced/separated and participants in non-marital relationships compared with married participants and participants with no relationship) [7]. Results from a case control study exploring risk factors for incident HIV infection in 2000 support these findings [30]. Another study showed a significantly higher risk of HIV infection in men (OR 6.51) and women (OR 4.75) who were unmarried but in a steady relationship, and men who were divorced/separated/widowed, compared to married individuals (OR 4.33) [29]. Hence having sexual relations with these groups could increase risk of HIV infection in Rakai.

The head of the local support group believes age difference between sexual partners contribute to increasing the numbers of HIV/AIDS cases. As mentioned in the introduction, studies have suggested that age difference between sexual partners (the female being younger) might contribute to increase HIV prevalence in sub-Saharan Africa [9-11]. A survey carried out in Rakai District assessed whether differences in age between sexual partners affect the risk of HIV 1 infection in female adolescents and young adults [39]. The study, using data from a trial completed in 1998, enrolled 6177 sexually active women. The participants completed a questionnaire and provided a blood sample for HIV 1 serology. The study found that 98.2% of all the participants had relationships with men who were of the same age or older. By the age of 15 years, half of all female adolescents had begun sexual activity, and by the age of 19 years, half were in marital or permanent consensual unions. The proportion of women with male partners 10 or more years older increased with age. Over 20% of women

aged 25-29 years had a partner more than 10 years older. There was a consistent association between older age of sexual partners and HIV 1 prevalence amongst the women. Prevalence of HIV 1 infection in female participants increased with older male sexual partners. It is unclear if age difference between sexual partners is targeted in current interventions. If not, the reviewed study and our findings suggest that this could also prove a target point in future interventions.

Over the past decade, there has been increased attention on the link between coercive sex and adverse health outcomes such as unintended pregnancies, non-use of contraception, gynaecological morbidity, and HIV infection [40]. Coercive sex is synonymous with forced sex, and may include rape, sexual assault, sexual abuse, sexual violence, sexual molestation, or other involuntary sexual activity [41]. A case control study from rural Uganda has shown a significant relationship between coercive sex and incident HIV infection for women reporting sex against their will compared to women not reporting (OR 7.84) [30]. It is important to note that it is uncertain whether this study was from Rakai District or not (not specified in the article), and the small number of participants (133 women included). Another community based survey in Rakai District in the period 1998-1999 aimed to explore the association between coercive sex and HIV [42]. One in four women reported having ever being forced to have sex against their will with their current partner. Coercive sex was strongly related to perception of their male partner's risk of being HIV positive. Women who perceived their male partner to be at high risk of infection experienced almost 3 times the risk of coercive sex, compared to women believing their male partners had low risk of HIV infection. The study found no significant association between HIV prevalence and coercive sex. In the reviewed literature we could not find evidence of association between coercive sex and HIV

infection in Rakai District. Coercive sex is not mentioned by our cases. It may however be a sensitive issue that needs a more careful approach and attention.

Because the individuals presented in the case reports were not randomly selected, the case reports cannot be considered as representative for a larger population. Case reports may give indications of problems on a population level, although some information may in some cases prove outright wrong. We believe therefore that costly interventions should be backed with results from scientific research. Used with caution, however, individuals may provide a list of useful issues that could be addressed when designing population-based studies. After 25 years with the epidemic in Rakai stigmatisation was still an issue for each of these cases and some of their contacts and may still have a detrimental effect on health. We conclude that more research is needed on how to make it easier for each individual to have friends and maintain family relations whilst approaching the institutions for testing services, treatment or assistance.

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9.0 Appendix

9.1 Objectives

Main objectives

Through the literature and through case reports we wished to explore the perceived and objective social factors that may contribute to the HIV prevalence and incidence in a rural district town in Uganda; and to explore the self-perceived implications of the HIV epidemic in a district in rural Uganda.

Specific objectives

1. Gather information through direct individual contact with local HIV positive residents.
2. Gather information from a local HIV support group
3. Gather information in the available literature on the following subjects:
 - (a) The use of condoms
 - (b) Efficacy of voluntary testing and counselling (VTC) as an intervention strategy.
 - (c) Exploring self-reported consequences of the HIV epidemic on individuals.
 - (d) Some population behavioural factors affecting the HIV epidemic in the selected area.
 - (e) Prevalence and incidence of orphanhood associated with HIV/AIDS.

9.2 Rakai Map

